

Title:

Enhancing the Prospects for Palliative Care at the End of Life: A Statewide Educational Demonstration Project to Improve Advance Care Planning

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Objectives: Although patients want to participate in discussions and decisions about their end-of-life care, studies show providers frequently fail to invite them to explore advanced care preferences or goals for living. The purpose of this demonstration project was to provide education and coaching to individuals, health providers and organizations across the state of Indiana intended to facilitate these conversations, documenting and honoring individuals' life goals and preferences for care in the final stages of life.

Methods: Education and training engaged community members as well as health care providers to: 1) improve participant comfort and facility discussing end-of-life issues; 2) improve knowledge of health care choices, including palliative and hospice care; and 3) prepare all participants to explore and document personal values, life goals and priorities as well as goals of care.

Results: Between January 2013 and June 2015, the team educated close to 5,000 participants. Participants' ratings of the quality and perceived usefulness of the events ranged from 4-5 (using 5-point scales; 5 = most effective). Participant comments were overwhelmingly favorable and indicated an intention to put the advance care planning resources, communication skills, knowledge of palliative and hospice care, and personal renewal techniques into practice.

Significance of Results: Participant motivation to foster advance care planning, discussions of palliative care, and end-of-life conversations was facilitated by the reframing of these conversations as identifying goals of care and priorities for living well in an important stage of life. Successful strategies included helping providers and patients to adopt a broader meaning for "sustaining hope" (not for cure, but for engaging in highly valued activities), developing provider communication skills and comfort in initiating potentially difficult discussions, engaging a new community health workforce who developed trusting relationship with patients in home-based services and fostering self-awareness and self-care among palliative care providers.

Key words/phrases: Skill development for end-of-life conversations; providers' self-awareness and self-care surrounding end-of-life care; community health workers' role in end-of-life conversations

Introduction

Communication about palliative care and advance care planning is critically important to improving care at the end of life by ensuring that persons with serious diseases are well-prepared to make informed decisions that align with their personal values and life priorities. Clinical guidelines recommend advance care planning for all patients with a chronic life-limiting illness (De Vleminck et al., 2014). Care planning improves alignment of patient care with patient wishes (Pew Research Center for the People & the Press, 2006; Silveira, Kim, & Langa, 2010; Tobler et al., 2012), increases patient and family satisfaction, and reduces surviving family stress and depression (Detering, Hancock, Reade, & Silvester, 2010). Optimally, care planning begins prior to the onset of disease, well before the end of life. Plans of care are developed through close collaboration between provider and patient, over multiple conversations (Silveira et al., 2010), grounded in a careful exploration and understanding of patient values, life priorities, and care preferences. These plans cover a wide range of needs specific to each patient and family, including pain and symptom control, psychosocial, spiritual, and practical needs, and emotional health (Shalowitz, Garrett-Mayer, & Wendler, 2006).

Unfortunately, this ideal is not often accomplished in practice. There is a growing body of literature that demonstrates patients with chronic illness want to participate in discussions and decisions about their care and to have these discussions (Johnston, Pfeifer, & McNutt, 1995; Steinhauser et al., 2001; California Healthcare Foundation, 2012; Pardon et al., 2012; Tobler et al., 2012; Morrison, 2013). Yet studies show that providers frequently fail to invite patients to explore advanced disease care preference (Anonymous, 1995; Tulskey, Fischer, Rose, & Arnold, 1998; Steinhauser et al., 2000; Earle et al., 2004; Detering et al., 2010; Keating et al., 2010; Agledahl, Gulbrandsen, Forde, & Wifstad, 2011; Nelson et al., 2011; Heyland et al., 2013; Wright, Zhang, Keating, Weeks, & Prigerson, 2014) or life goals. When family members are placed in the stressful situation of guessing what a loved one might want, these predictions have been shown to be incorrect approximately one third of the time (Unutzer et al., 2002). Thus many patients' values and goals go undocumented and patient care preferences remain unknown (Earle et al., 2004; Detering et al., 2010; Boustani et al., 2011).

There are many barriers to advance care planning. Providers, trained to cure disease, may be reluctant to discuss death and dying (2014). Many providers have inadequate training in communicating about difficult subjects and in advance care planning (Greutmann et al., 2013). Health systems may lack a clear protocol regarding who should initiate advance care planning and in what setting (Gott et al., 2009) and may lack structural support for planning, such as repositories for documentation, or support for provider time to explore patient values, priorities and preferences (2014). Patients and families may feel uncomfortable bringing up the topics of advanced disease and death. The recent Institute of Medicine report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (2014) calls for research to improve the models, processes and technologies of advance care planning to increase patient, family, and provider participation in the planning process (Katon et al., 2005).

As the U.S. population continues to age, there is a growing need to improve the process and technologies of advance care planning for older adults with chronic disease to ensure that the care they receive is aligned with their personal preferences, priorities, and values (Sherbourne & Stewart, 1991; Bernard, 1994; *Doing Qualitative Research: Methods for Primary Care*, 1999; Kroenke & Spitzer, 2002; Horsman, Furlong, Feeny, & Torrance, 2003; Bakitas et al., 2004; Patel, Sinuff, & Cook, 2004; Callahan et al., 2005; Katon et al., 2005; Austrom et al., 2006; Callahan et al., 2006; Spitzer, Kroenke, Williams, & Lowe, 2006; S. R. Counsell et al., 2007; Department of Health, 2008; Steven R Counsell, Callahan, Tu, Stump, & Arling, 2009; Glaser & Strauss, 2009; Baughman et al., 2012; Working Group on Health Outcomes for Older Persons with Multiple Chronic Conditions, 2012; Cottingham AH, 2014; Kirolos et al., 2014).

From 2012-2015 the Walther Cancer Foundation funded an education team (the Walther Education Team) to provide education and coaching to individuals, health providers and organizations across the state of Indiana to facilitate conversation, documentation and honoring of individuals' life goals and preferences for care in the final stage of life. In this paper we describe that work and lessons learned.

Methods

The Walther Team was comprised of four educators (DKL, AHC, WG, SI) and one evaluator (TI) selected for the project based on their previous work in community health education, interprofessional team education, communication skills development, personal and professional renewal, and organizational change. The Team grounded its work in the recognition that end of life is an important stage of life. Individuals in this phase face concerns related to health as well as relational, spiritual, emotional and practical issues all of which may influence goals of care.

Advance thought and planning enable individuals to identify and articulate personal priorities and preferences and better achieve individual life and health care goals. The Team provided education to community members, health care providers and health systems to improve participant comfort and facility discussing end-of-life issues; improve knowledge of health care choices, including palliative and hospice care; and prepare all participants to explore and document personal values, life goals and priorities as well as goals of care to help each individual achieve her/his highest possible quality of life.

Cultivating Willing Partners

The Team's statewide educational strategy targeted both community members and health care professionals with a goal to activate both patients and providers to initiate conversations about life priorities and goals of care. Surprising to us, while many of the community organizations and health teams and systems we approached in year one agreed that education in this area would be highly important for their constituents, very few were initially eager to present the topic. Most shared concerns that individuals would not want to participate in conversations related to end of life. With persistence, the first few sessions were scheduled. The team was able to rely on these early successes and identification of "best fit" venues to engage additional partners. Demand grew each year.

Educational Strategy

The Team created a core of educational sessions that could be customized to meet the specific educational needs and available time of each audience. All learning experiences were grounded in adult learning theory, (*How People Learn: Brain, Mind, Experience, and School*, 2001) and were interactive as well as case-based. We intentionally created learning experiences that participants would find relevant

and immediately useful. Stories written by providers and patients about their real life experiences were the foundation of each session, accompanied by prompts and discussions designed to foster quick translation of new knowledge, skills and attitudes gained into participant daily practice. Many sessions included narrative writing strategies to foster the development of participant self-awareness and prepare providers to invite patients into end-of-life care conversations that may initially feel uncomfortable to the provider as well as the patient. The length of the sessions varied from 1-hour mini-sessions to multiple-day events.

Overview of Educational Sessions

Community-Focused Learning Experiences

Community presentations and workshops were designed to help participants 1) better understand the importance of identifying personal priorities and planning for care at the end of life or a time when they may not be able to articulate their own health care preferences; 2) begin to think about a wide range of life priorities, goals and preferences for care that they may want to address in their later stages of life; and 3) understand and begin to complete the specific processes involved in documenting and communicating preferences for life and for care. Participants were introduced to the *Conversation Project Starter Kit* (Institute for Healthcare Improvement, 2015) (<http://theconversationproject.org/starter-kit/intro/>) and learned to use decks of *Go Wish* cards (Coda Alliance) (<http://gowish.org/>) to define and begin prioritizing their preferences for care. They received copies of and instructions for completing Indiana Advance Care Planning legal forms including “Appointing a Health Care Representative” (one witness required), Health Care Power of Attorney (one witness plus a notary’s witness signatures required), Living Will Declaration (two witnesses’ signatures required), Indiana Advance Directive (two witnesses’ signatures required – if individual wants his/her HCR to have additional powers of Medical Power of Attorney, then one witness must be a notary). They also received copies of and instructions for completing Indiana legal forms and received a list of key advance care planning websites and resources. Please see Appendix I.

Health Care Provider Learning Experiences

Provider presentations and workshops focused on the importance of communicating with patients about end of life, and exploring patient life priorities and goals of care and communication skills and strategies that would facilitate these conversations. Grand Rounds, noon presentations, webinars and similar events introduced key topics and provided a context for the importance of planning. Half- day advanced communication skills workshops were conducted for providers and teams who wanted to enhance their ability to communicate with patients and families about topics related to end-of-life and care planning. These included: 1) disclosure of prognosis; 2) responding to patient and family emotion; 3) exploring patient values and life priorities; 4) describing palliative and hospice care options along with curative treatment; 5) helping patients identify goals of care; and 6) exploring provider personal beliefs and perspectives that might impact conversations with patients on these topics. The workshops presented both broad communication strategies for initiating and facilitating conversations over time as well as skills specific to effective interpersonal dialogue. Events were attended by a wide variety of health care providers including primary care providers, specialty care providers, social workers, chaplains, physical therapists, music and art therapists, medical, nursing, social work, and physician assistant trainees as well as members of palliative care teams.

Taking Planning to the Home: Educating Community Health Workers

The Team recognized that a wide range of individuals could successfully accomplish end-of-life planning. Members had been recently working to educate a team of 20 community health workers [called Care Coordinator Assistants (CCA)] to provide in-home education and coaching for patients and caregivers, and realized these individuals were capable and well positioned to initiate conversations about goals of care, life priorities, and other topics related to advance care planning with patients and families. We developed a series of 5 four-hour workshops for these providers, implemented over a 5-month period. The educational sessions were reinforced through thirteen 2-hour follow-up case conferences. The training prepared CCAs to identify the level of patient readiness for discussing life priorities and goals of care and conduct a series of guided conversations to help patients: 1) identify appropriate health care representative candidates; 2) review prior experiences of health, illness and hospitalization as a

framework for considering current care preferences; 3) consider what brings most meaning to their lives and what might be most important for them to maintain, achieve or avoid in the future (for example relationships with family, connection with church, maintenance of a home, family financial security, etc.); and 4) identify specific preferences for care.

During this time, we also worked with electronic health record (EHR) programmers to create and test a custom built clinical decision support (CDS) tool, added to our internally built Aging Brain Center EHR to support the CCAs' work with patients. This CDS tool included prompts for gathering and assessing bio-psycho-social-spiritual history, needs, and care preferences, healthcare representative/power of attorney and POST forms, and other key information. Interest in home-based advance care planning spread to Area Agencies on Aging (AAA) around the state and the Walther Team conducted training sessions ranging from 2-8 hours for community health workers employed by the AAA.

Institutionalizing Planning

Several healthcare organizations requested facilitation of organizational strategic planning to develop the institutional infrastructure that would support expanded and routine goals of care discussions and advance care planning. These events provided an overview of current innovations at institutions around the country designed to foster a culture of conversation, planning and documentation of patient preferences for care and life priorities and goals. Each session included time for institution administrative leaders and key providers to chart long- and short-term initiatives to create a "Conversation Ready" culture in their own institution.

The Courage to Care

Recognizing that caring for patients with advanced diseases can be challenging for providers, and in response to early provider requests, the team adapted a series of provider renewal retreats entitled *Courage to Care: Honoring Our Patients' Preferences*. *Courage to Care* is based on Parker Palmer's *Courage to Teach* programs and consists of a series of four seasonal retreats (some teams have requested more than four retreats) focused on personal and professional renewal that foster reflection on the connection between the world of inner experience and the outer world of caring for patients with

advanced disease. In large-group, small group and solitary settings, participants explore the “courage to care” using stories from their own journeys, and insights from poets, storytellers and diverse wisdom traditions.

Evaluation

Evaluation includes continuing education-style survey data completed by participants immediately following each of the events. Additionally, we included narrative reflective writing pieces, which were completed over a three- to twelve-month period following the education sessions to evaluate what providers were actually incorporating into their practice and mindset as part of our communication skills and retreat sessions. The narratives have been collected and de-identified for qualitative analysis looking for themes and changes in themes with groups who are participating in multiple events over time.

A variety of evaluation instruments were used to characterize the impact and quality of the educational engagement with target audiences. On some occasions (for example, in the “Conversation Starter Events”), the instrument used was designed by the Walther Education Team itself. In other circumstances (for example, in Grand Rounds/Noon Conference style events), the instrumentation used was that mandated by the host institution. In the results that follow, efforts are made to integrate the evaluation metric across the diverse repertoire of educational events, often using a comment on the various instruments’ 5-point evaluation scales used to assess the merit of the activity.

Results

The Walther Team conducted over 100 events and served close to 5,000 participants in Indiana over a 2 ½-year period.

(Insert Table 1 here)

Participants’ ratings of the quality and perceived usefulness of the events ranged from 4-5 (using 5-point Likert scales; 5 = most effective) on post-event surveys. Where sessions were reiterated over time, rating increased in later sessions to near-perfect scores. A more detailed summary of quantitative and qualitative evaluations by event type follows.

"Conversations with Our Loved Ones" and other Lay Community Learning Experiences

"The whole program was wonderful. I was able to open my mind to areas I had not thought about before."

Community Member 2014

Thirty-three 1 to 2-hour community workshops were held between April 4, 2013 and May 14, 2015. The individuals who participated in these workshops were most often lay citizens of various communities in Indiana, but also included hospital-based professional education teams, physician assistant students, and senior center personnel. The small discussion groups in these communication starter events were uniformly successful, well received, and characterized as useful. Participants across all events were grateful for the opportunity for dialogue, education on choosing a Healthcare Representative and back up, as well as the resources provided to assist participants in defining their own preferences for care. Favorable comments emphasized the relevance of the *Go Wish* cards as a useful technology for prioritizing palliative care-supported activities near the end of life. In the view of the participants, the sessions provided practical suggestions and featured good resources for use after the session.

Overall, it is clear that these public education workshops were very favorably received. Whatever initial organizational reticence there might have been to engage the public in discourse around the topics of palliative care, advance directives and care near the end of life disappeared over time. Acknowledging that it might be difficult to open ‘conversations’ about such matters, even within families, but providing resources to use in opening and pursuing questions about advance-care preferences was clearly key.

Introductory Sessions in Advance Care Planning for Healthcare Providers

"The sessions helped improve my understanding of palliative care and the patient's view of end of life and provided helpful ways to have conversations about these with patients."

Provider, 2014

Fourteen introductory sessions, including Grand Rounds, Noon Conferences and Panel Discussions) were held between January 30, 2013 and November 11, 2014. Evaluations of these activities were highly favorable, ranging from 4.2 to 5 (5=excellent) on the typical five-point scale rating

session quality and usefulness. Qualitative evaluative responses to these sessions featured favorable commentary on the use of teaching stories, recognition of the critical importance of communication behaviors, appreciation for education on palliative and hospice care, and the relevance of the information and tools presented to the participants' professional needs.

Communication Skills Training Workshops for Health Care Providers and Teams

"I will make a more conscious effort to validate each patient's feelings and identify what is important to them."

Health Team Member 2014

Thirteen communication skills workshops ranging from 2 - 4 hours were conducted between January 24, 2013 and April 9, 2015. These workshops were clearly extremely well received with ratings of Excellent or Very Good evaluations from over 97% of participants. Themes from the qualitative analysis of open-ended evaluation responses included the interprofessional educational approach, which focused on health teams, with participants expressing appreciation for gaining greater understanding of the perspectives of different disciplines, as well as appreciation for education and training emphasis on talking with patients about palliative and hospice care. Participants also identified planned changes in future practice based on enhanced knowledge, skills or attitudes facilitated by the workshop. Themes included plans to explore patient health and life priorities, to spend more time eliciting and listening to patient thoughts and concerns, and to implement new skills in responding to patient emotion and negotiating family conflict around goals of care.

Advance Care Planning Communication Training for Community Health Workers

"After listening to my patient talk about her siblings and what they went thru when they died, I knew it was the right time to talk about advanced directives. I started with the 'Go Wish' activity and then worked with her to identify a health care representative and then complete a living will document. This occurred during two visits."

Community Health Worker, 1 Year Post Training

Ten 1 to 8-hour advance care planning training sessions and fourteen case conferences were conducted for community health workers. Likert-scale overall evaluation ratings of these sessions by 16 participants were high, averaging 4.7 on a 1-5 scale. Scores averaged 4.8 on a 1-5 subscale evaluating the education as “excellent and important in my work.” Themes in qualitative analysis of text comments on the sessions included strong allusions to the importance of developing trusting relationships with patients and family members, the importance of having these discussions in home settings where patients and family are in familiar surroundings and comfortable, the complexity of interactions with frail/sick/demented patients and members of their family, the need to spend time listening carefully, the need to establish an understanding of the difference of the power of attorney and health care representative documents, the need to take time to decide on who will serve as a health care representative, the necessity of community health worker persistence and respect for those they serve, the helpfulness of resource materials such as *Go Wish* cards, and the importance of sharing and learning from problematic situations encountered with team members.

In the three Area Agency on Aging 2015 workshops, evaluations included ‘action items.’ After the February 19 workshop, 86% of the respondents reported that they are “better able to explain potential Advance Care treatments such as CPR, intubation, artificial hydration and nutrition.” After the March 19 workshop, 96.8% of respondents affirmed that, “I will use the communication skills I learned to begin conversations about advance care planning with my clients.” Among the same respondents, 92.6% affirmed that, “I will explore clients’ personal life priorities and preferences and use those to guide our conversation about advance care planning. These same items were responded to affirmatively after the May 4, 2015 workshop by 100% of participants.

Provider Renewal Retreats: “*Courage to Care: Honoring Our Patients’ Preferences*”

"The question this retreat raises for me: How can I touch this tender, human, rejuvenated place on a regular basis?"

Team Member

Six 1.5-day retreats and three brief retreats for palliative care teams were held between May 2, 2013 and October 1, 2015. The purpose of these retreats was to foster professional development and personal formation to facilitate the growth of “mindful practitioners,” individuals capable of integrating personal awareness with their professional role. The evaluation approach emphasized narrative journaling rather than quantitative ratings. These reflections highlighted the importance of developing the inner capacity to be open to others in this work. One participant commented: "How can I continue to use my own brokenness to open myself to greater empathy?" Participants shared a recognition that their own personal histories resonated with the suffering, healing and brokenness of their patients. They noted the challenge of needing to be fully present to patients and each other as well as being committed to specific tasks in the busy life of a practitioner. Others noted the importance of creating “safe spaces” to “go deep,” and the need for time and situations that permit self-care as well as quietness and centering.

Narrative journaling also provided the opportunity for reflection specifically on the participants' experiences of with patients. In their journaling providers reflected on caring for persons in life circumstances very different from their own, including persons they might in other circumstances disdain. These reflections revealed the ability to form strong relationships across such differences, learn from these individuals, teach other members of these patients' families things they didn't often know about their own loved ones, use this information and these relationships to provide guidance and facilitation for care near the end of life, contribute to funerals, facilitate reunions joining patients and children with whom they have lost contact, and even support celebration of anniversaries or birthdays near the end of life. Practitioners, on the basis of their own experience, learn to not pass judgment on others and to be open to what they as practitioners might contribute to all patients. Again and again, participant reflections on their work in palliative care affirmed the importance of recognizing patients as unique persons but also “stepping out of my comfort zone” as a provider to join with these individuals and their families while remaining open to their needs and holding in abeyance the practitioner's own expectations or judgments.

One team engaged in a sequence of retreats over multiple years. Reflections from this team suggest progressive learning over time. The qualitative evaluation of narratives was noteworthy for the

development as a new ‘natural language’ within the team from the retreats themselves (e.g. increasingly common use of terms such as ‘going deep’) and the acceptance of shared concepts (e.g., self-care and self-knowledge is important to my ability to care for patients and their families – not merely as respite but as a foundation for professional growth and maturation).

Discussion

The Walther Team learned a lot in this statewide education initiative – from the initiative’s processes, its evaluation, and in our own reflections on the activity. While the lay press and medical literature frequently describe the importance of advance care planning, palliative care, and careful attention to eliciting patient end-of-life goals, we quickly discovered major initial resistance to moving the good idea of having “the conversation about end-of-life care” into action. In our localities, and among all stakeholders, there remains a high level of discomfort in our culture in talking about advanced disease care and death. Health care providers (HCP), in particular, expressed anxiety that talking about poor prognoses, terminal illness, and preparing for death, even when death is imminent, might “take away hope.” In the natural language of providers, “hope” alluded to aspirations for biomedically framed disease cure rather than hope for bio-psycho-social-spiritual wellbeing in a broader framework of care.

Early in our work we decided that we needed to focus on opening conversations among patients and families and all other stakeholders involved in care, not about dying, but about what ‘hope’ might mean to individuals with advanced disease as they transition into a late stage of their life. In this reframing, each person’s story was to be understood and uniquely situated within their ring of loved ones who are often inextricably linked to the individual’s interests, pleasures, dreams, hopes, and understanding of their current state of health and well-being. Our work became centered on aspirations expressed in Dame Cicely Saunder’s (founder of the modern hospice movement) famous quote: “...we will do all we can, not only to help you die peacefully, but to also live until you die.” Our Team goal became one of using educational and training methods to move this aspiration into action by helping individuals involved in this process of care begin to clarify patients’ personal goals for “living well until you die.” To do this work comprehensively, we decided that we needed to establish a broad frontier for education, one in

which we engaged with all stakeholders in this care process – lay citizens, health care providers, community health workers, and palliative care teams. In the complex, responsive web of end-of-life care, to affect one of these communities and not others seemed unlikely to systemically advance the prospects of palliative and person-center care.

Among lay community members, we learned that normalizing the process of reflecting on advanced disease goals of care began with building conversations into comfortable, routine activities such as a card game at a senior citizen's event and revisiting perfunctory paper work completed years ago to make sure these documents reflect current goals and decisions. We found that community members can have conversations about end-of-life care without being overly somber. While using the *Go Wish* cards to identify preferences for care, we were surprised to hear laughter as participants tried to narrow their list of most important goals to their top 10 preferences. Typically, we also heard animated conversations among participants as they compared their lists of preferences. In the process we discovered that most participants had not completed any documentation prior to our workshop, or had completed forms "years ago" that in many cases named powers of attorney and health care representatives long since deceased or estranged from the person who had completed the forms. At the end of each workshop, we asked each person to write down what actions they needed to do next leaving them with their personal plan of action.

In our engagements with health care professionals, we were quickly reminded that they are accustomed to helping patients and their families through the stages of health maintenance, acute illness, and chronic disease management relatively comfortably until their patients are approaching the end of life. Little is taught or modeled in many health professional schools about how providers can help patients transition to "a new normal" and identify new, stage-appropriate goals for living and for care near the end of life. Many providers, even those who most frequently care for patients near the end of life, were uncomfortable openly exploring non-curative care options with patients, and were unsure how to approach or facilitate conversations about patient life priorities at this stage of their life. We found that using provider and patient stories of end-of-life experiences, both rewarding and disappointing, resonated instantly with most participants, and provided helpful examples for handling difficult, emotionally

charged, interactions with patients. We also found that many providers lacked basic skills in interpersonal communication, as well as more advanced skills in facilitating difficult conversations. Having the opportunity to practice and get feedback in a safe space gave them the opportunity to try out different approaches and find a style that worked well for them. Another benefit we observed was the opportunity for providers to hear the approach used by their colleagues from different professions. Physicians, chaplains, nurses and social workers all heard the somewhat distinct languages used by each profession and were able to appropriate words and concepts to create a personal approach.

We also found that an important method for normalizing and sensitizing HCP about the “felt” importance of their role in having “conversations” with their patients was to be immersed in the same sessions we had community members attend. Couched as training, HCPs experienced the emotional and cognitive challenges of going through a parallel process of thinking about and prioritizing goals for living and identifying someone to speak for them when they might not be able to speak for themselves. Conversations often turned to thinking about these issues for their aging parents and the potential consequences that avoiding these conversations could have in producing family conflict and pain and psychological suffering. Even when willing and trained to have these conversations, however, HCPs often remained unable to find the time or appropriate setting for these conversations with their patients during busy outpatient clinics, frantic emergency department visits, and hospital stays triggered by episodes of acute medical decompensation.

Knowing that there are too few health professional providers to attend to advance care planning, especially since these discussions might most comfortably take place in the homes of patients and not a “once-and-its-done” event but rather a series of conversations, we imagined that community health workers (CHW) given the skills and practice needed to engender their self-confidence, could develop trusting relationships with patients and family over time making substantial progress in evolving “conversations” in less-hurried and caring ways. Training CHWs caring for patients in both medical settings and home settings proved instrumental in creating a culture in which soliciting and honoring patients’ preferences for their end-of-life care was considered routine standard of care.

The CHWs were initially hired to care for elderly patients and their caregivers and were reluctant at first to take on the role of initiating “the conversation.” As they grew in experience in their roles, CHWs moved well beyond saying that advance care planning was “not in their job description” to commenting positively on their growing confidence in their ability to use their new ACP skills. They expressed their surprise that patients were eager to have these conversations and once trust was established how willingly patients shared their hopes, wishes, and dreams. Certain tools (e.g. *Go Wish* cards) were particularly helpful in opening the door. Documenting what had been accomplished in the electronic medical record (EMR) was important to help ensure wishes were available at points of care (e.g. in the emergency department, hospital, clinics), although more work on interoperability among EMRs is still needed. More specifically, documentation of officially appointed Health Care Representatives, Living Wills, preferences about artificial nutrition, and goals of living facilitated medical decision making during hospital admissions and emergency.

Finally, palliative care (PC) team members and others deeply engaged in end-of-life care also benefited from education and training. The importance of self-awareness and self-care stood out as essential to sustaining oneself in the deeply engaging and intimate work of helping patients and families move to clarify their goals for living and how to personalize this process. Self-awareness work came to be recognized by these teams as critical to achieving and maintaining selfless, empathic care of patients who often might be very different from, and from different walks of life than the HCPs. Our work seemed to allowed providers to grow *with* their patients through shared consciousness-raising and skill-building work.

In Closing

We learned that a comprehensive, stepwise approach to promoting end-of-life conversations was facilitated by a reframing of the conversation as goals for living well near the end of life. Any effort to influence cultural change requires attention to the many important stakeholders and identifying key change nodes such as: addressing provider’s fears and anxiety; helping providers and patients to clarify the broader meaning of “hope” and develop the communication skills and confidence needed to initiate

these difficult conversations. Advancing the prospects for palliative care near the end of life may include training a new workforce who develops trusting relationship with patients, especially in home-based services. In a broad territory for education fostering self-awareness and self-care among palliative care providers who can then more deeply grow into their work is important. Activating community organizations and their lay members to help ‘normalize’ the difficult conversation about end-of-life priorities and care, while empowering them to articulate their goals for living and end-of-life preferences with family, friends, and health care providers is a foundation for all these efforts. As next steps, we are currently working to train health care providers employed by our statewide Area Agencies on Aging (AAA) who build trusting relationships with their elderly and disabled clients during repeated home visits. Our EHR and clinical decision support tools, with built in support for guiding and documenting advance care planning conversations, have been made available to all AAA staff for their use.

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Table 1. Summary of Walther Education Events-January 2013 to June 2015			
Type of Event / Type of Participant	# of Events	Duration of Event (\bar{x})	# of Participants
ACP Interactive Workshop for Community Members	33	1 – 2 hr (\bar{x} 1.5)	966+
ACP Training for Community Health Workers	24	1-4 hr (\bar{x} 2)	590+
End-of-Life Care, ACP and Communication Skills Training for HCP (Interprofessional)	27	0.5-4 hr (\bar{x} 1.5)	1076+
Renewal Retreats for HCP (Interprofessional)	9	2-11hr (mode 11)	154+
End-of-Life Care and ACP Strategic Planning for HC System	3	2 hr (\bar{x} 2)	40
Poster Presentation for HCP (Interprofessional)	4	1 hr (\bar{x} 1)	740+
Health Fairs for Community Members	3	3-5 hr (\bar{x} 4)	1300+
Total	103		4866+

ACP=advance care planning HC=Health Care HCS=Health Care System; \bar{x} = mean.

Appendix 1: Helpful References for The Conversation

Helpful References for The Conversation

www.TheConversationProject.org The Conversation Project's home page; Free access to "The Starter Kit", stories, etc.

www.prepareforyourcare.com A user-friendly Online Advanced Care Planning Tool (including several videos). You can view this website with your friends & family.

www.agingwithdignity.org Home page; access to "Five Wishes" package. **(\$5 to print or to use online)** This is a very helpful workbook to complete but **is not recognized by Indiana** as an official Advance Directive

www.PracticalBioethics.org Home page; access to "Caring Conversations" workbook. **Is not recognized by Indiana** as an official Advance Directive but a good guide to use in planning.

www.abanet.org/aging/ Free access to "Consumer's Tool Kit for Health Care Advance Planning;" videos to explain legal terms, etc.

www.centerforhospice.org/document.doc?id=11 The "Appointment of Health Care Representative" form.

<http://www.in.gov/isdh/25880.htm> **Official site for the Indiana Advance Directive** as well as other forms related to planning for your own health care.

<http://www.iupui.edu/~irespect/POST.html> Information specifically on the new **POST** form

www.CaringInfo.org Free resources from Caring Connections. Especially check out free brochures; Review their community outreach and their **Speak4me** campaign.

<http://gowish.org> Play the **Go Wish card game** online at this website. Go to this site, scroll down until you see "Try It Free", click on this and play the game. When you are finished arranging the cards, you may print out a copy of your selection/arrangement.

<http://www.mydirectives.com> Platform for completing and storing your advance directive, **free**

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